

Testimony Before the Subcommittee on  
Criminal Justice, Drug Policy and Human Resources  
Of the Committee on Government Reform  
Of the U.S. House of Representatives

Oversight Hearing on  
“Federal Health Programs and  
Those Who Cannot Care for Themselves:  
What Are Their Rights,  
And Our Responsibilities?”

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Mr. Chairman, Vice-Chairman, members, thank you for the opportunity to address this Subcommittee. My name is Diane Coleman. I have a Juris Doctorate and Masters in Business Administration from the University of California at Los Angeles, and am a member of the California bar, on inactive status. During the last twenty years, I have been employed first as an attorney for the State of California, then as Co-Director of an assistive technology center in Nashville, Tennessee, and now I am the Executive Director of Progress Center for Independent Living in Forest Park, Illinois, a nonprofit nonresidential service and advocacy center operated by and for people with disabilities.

I have had a neuromuscular disability since birth, and have used a motorized wheelchair since the age of eleven. From 1987 through 1995, I volunteered as a national organizer for ADAPT, also known as the American Disabled for Attendant Programs Today. I continue to advocate, speak and guest lecture on long-term care issues within Illinois.

In April, 1996, I founded Not Dead Yet, a national grassroots disability rights organization opposing the legalization of assisted suicide and euthanasia. I have twice presented invited testimony before the Constitution Subcommittee of the Judiciary Committee of the U.S. House of Representatives (April 29, 1996 and July 14, 1998) on the topic of assisted suicide. Over the last decade, I have appeared regarding assisted suicide and euthanasia on *Nightline*, *CBS Up To the Minute*, *ABC World News Tonight*, *CNN*, *Court TV*, *CBS Evening News*, *MSNBC's The Abrahms Report*, *Fox News* and *National Public Radio*, among others. I co-authored Amicus Briefs filed in the U.S. Supreme Court on behalf of Not Dead Yet and ADAPT in the matter of *Vacco v. Quill* (1996) and in the *Conservatorship of the Person of Robert Wendland* in the California Supreme Court (2000). In 2003, I joined the adjunct faculty at the University of Illinois at Chicago to co-teach a series of graduate courses in disability and medical ethics.

First, I would like to thank Congressman Danny Davis for his leadership in sponsoring MiCASSA, the Medicaid Community Attendant Services and Supports Act, which would give people with disabilities, old and young, the choice to receive long term care services in their own homes rather than being forced, for lack of alternatives, into more expensive and dehumanizing nursing homes and institutions. For an in-depth substantive discussion of MiCASSA and Money Follows the Person legislation, I would like to refer you to the written testimony of Bob Kafka submitted for this hearing. I hope that many more of you, from both sides of the aisle, will soon add your names as co-sponsors of this important proposal.

When I was six years old, my doctor told my parents that I would not live past the age of 12. A few years later, the diagnosis changed and so did my life expectancy. Over time, I learned that respiratory issues would probably develop. I have friends who've used nighttime ventilators for years, so I knew what symptoms to watch for, and three years ago, started using a breathing machine at night. I had two other friends in Nashville, one in her 30's and one in her 50's, who needed the same thing. But their doctors discouraged them from it, reinforcing their fears, and either didn't know or didn't disclose what the medical journals said would happen as a result. At an early age, they each went into respiratory distress, and died within a month from infections. A number of my other friends have been pressured by hospital employees to sign do-not-resuscitate orders and other advance directives to forego treatment, coupled with negative statements about how bad it would be if they became more disabled. Frankly, I'm becoming

worried about what might happen to me in a hospital if I have a heart attack or other medical crisis. I have appointed my health care proxy, but will the decisions I have entrusted to him be followed by my health care providers? I am not at all convinced that decisions to live are any longer treated with the same respect by health care providers as decisions to die. In fact, I am sure they are not.

Nine years ago, I was on my way to testify before the House Constitution Subcommittee about the opposition to legalized assisted suicide coming from national disability rights organizations. Many of us were worried about Jack Kevorkian, whose body count was 70% people with non-terminal disabilities, and we were worried about two Circuit Courts declaring assisted suicide a constitutional right. We had begun to think that we needed a street action group like ADAPT to address the problem, and it was actually the head of ADAPT who thought of our name, taken from a running gag in Monty Python and The Holy Grail, Not Dead Yet. From our viewpoint, assisted suicide laws would create a dangerous double standard for society's response to suicidal expressions, an unequal response depending on one's health or disability status, with physicians as gatekeepers. That sounds like deadly discrimination to us and, frankly, we've been disappointed that the U.S. Dept. of Justice didn't use our civil rights law, the Americans With Disabilities Act, to challenge the Oregon assisted suicide law. Like other minority groups, we feel that discrimination is best addressed on the federal level, and states rights have too often meant states wrongs. To date, eleven other national disability rights organizations have adopted Not Dead Yet's position opposing legalized assisted suicide.

It wasn't long before the problem of non-voluntary and involuntary withdrawal of food and water also moved onto Not Dead Yet's radar screen. Before Terri Schiavo, there was Robert Wendland in California. Both his wife and mother agreed that Mr. Wendland was not in a persistent vegetative state, and that he had not left clear and convincing evidence of his wishes. Nevertheless, his wife argued that she should be able to remove his tube feeding anyway, and Dr. Ron Cranford was on the scene to support her. A state statute, based on a national model health care decisions code, gave her the right to starve and dehydrate him, and forty-three bioethicists filed a friend of the court brief in agreement. Ten disability rights organizations filed against the general presumption that no one would want to live with his disabilities, being used to justify lowering constitutional protections of his life. Ultimately, the California Supreme Court agreed with us that his life could not be taken without clear and convincing evidence of his wishes.

By the time the Schiavo case reached major national attention in 2003, twenty-six national disability organizations had taken a position that Terri Schiavo should receive food and water, due to the highly conflicting evidence of her wishes and the fact that she had not chosen her own guardian. Attached to my written testimony is a three page statement issued by twenty-three such groups in October 2003, and a more recent article co-authored by Steve Eidelman, head of the Arc of the United States, and Stephen Drake, research analyst for Not Dead Yet. We were deeply disturbed to see court after court uphold questionable lower court rulings. This time, 55 bioethicists supported the removal of food and water. We were also disturbed that the court allowed most of Terri Schiavo's rehabilitation funds to be spent on her husband's lawyers, that she was denied a properly fitted wheelchair, a swallowing test, swallowing therapy, the potential for oral feeding, speech therapy, and the freedom to leave the hospice with her parents, even temporarily. And we were concerned that adult protective services did not intervene, and the

state protection and advocacy agency tried but proved powerless. It would appear that the prevalent prejudice that no one would want to live like Terri Schiavo translated into her guardian's unfettered right to treat her at best as a prisoner, at worst as though she was already dead.

Nevertheless, the perspectives of such prominent national groups as The Arc of the United States (formerly the Association for retarded Citizens), the National Spinal Cord Injury Association, the National Council on Independent Living, and many others were consistently ignored by most of the press, as well as the courts.

Unfortunately, the anecdotal evidence suggests that Terri Schiavo's case may be the tip of a very large and almost fully submerged iceberg. I've been a health care advocate for a couple decades, often joining street protests against government health cuts. One mission of the end-of-life care movement is a good one, to educate health care providers about how to provide good palliative care, but another mission is to shape public policy on health care. It appears that a certain line of thought in bioethics has pretty much taken over the policy-making work. This line of thought involves a lifeboat approach, deciding who gets thrown out.

When we analyze, why have the pro-life and religious advocates received such disproportionate attention, we are forced to conclude that disability rights advocates don't fit a script that everyone else seems determined to follow. For the last three decades, certain bioethicists have told the press and the public that euthanasia is about compassionate progressives versus the religious right. Never mind that these bioethicists are actually talking about the legal parameters for statutory guardians and health care providers to medically end the lives of people with disabilities on a discriminatory, non-voluntary or involuntary basis. Never mind that it takes more documentation to dispose of our property than to dispose of our lives. Concerned disability groups don't fit the script and so we have been marginalized or ignored entirely.

Here's how I'm beginning to look at things. The far right wants to kill us slowly and painfully by cutting the things we need to live, health care, public housing and transportation, etc. The far left wants to kill us quickly and call it compassion, while also saving money for others perhaps deemed more worthy.

The lifeboat bioethicists who have shaped this debate apparently think of themselves as progressives, but they never seem to discuss cutting unnecessary health care marketing costs or profits before cutting lives. My sister recently started a new career as a medical assistant at a practice with 25 doctors in Michigan. She said that four days out of five, she doesn't have to buy lunch because it's catered in by pharmaceutical companies. Marketing costs. But rather than spending all that professional brain power on conquering the waste and inhumanity of a profit-driven health care system, these bioethicists are pushing new health care decisions laws to kill disabled people who aren't going to die soon enough for their taste without a little push.

Why make it easier for guardians to refuse food and water on behalf of persons who cannot speak for themselves? In a 1983 article, over two decades ago, reflecting on the possible outcome of this food and water debate, Daniel Callahan, then director of the prestigious Hastings Center, wrote that "...a denial of nutrition, may, in the long run, become the only effective way to

make certain that a large number of biologically tenacious patients actually die." He further predicted, "Given the increasingly large pool of superannuated, chronically ill, physically marginal elderly, it could well become the *nontreatment* of choice." [Daniel Callahan, "On Feeding the Dying," *Hastings Center Report*, October 1983, p. 22.] The script was written long ago.

And please note, many people in nursing homes are on feeding tubes not because they can't eat orally, but because there are not enough staff to help them eat. One study also found that in for-profit nursing homes, African-Americans with dementia will be taken off hand feeding and put on a feeding tube sooner in the disease process than their white counterparts. Abracadabra, they're on "life support," the kind that can be removed.

One of the leaders of the end-of-life care movement, Dr. Ira Byock, was interviewed by *Ragged Edge Magazine*, a leading disability rights publication. He stated that Partnership for Caring and Last Acts, national leaders in the movement until they disappeared under a cloud late last year, had excluded the disability perspective, and that this exclusion was "deliberate and irresponsible." What's especially disturbing is that they had fifteen years and hundreds of millions in funding from prominent foundations, and set up surrogate decision-making protocols to end the lives of people with intellectual disabilities, without seeking the input of such individuals and the established organizations that address issues of self-determination for people who have less typical ways of receiving, processing and communicating information.

What might other disability groups have brought to the discussion table?

I recently read a journal article about the problems with advanced directives. A consistent finding in several funded studies is that people change their minds about what treatments they want, and what level of disability they will accept, as they move through the experience of having increasing disabilities. The disability community has a response to that, to use a popular phrase, "well, DUH."

And you may have seen reports of a new Alzheimer's study last year. It confirmed previous studies that caregivers have a lower opinion of their relative's quality of life with Alzheimer's than the persons themselves have, and found an explanation for the discrepancy. It seems that the caregivers project their own feelings of the burden of care-giving onto the person they care for. Once again, the disability community response is "well, DUH." And these are the very caregivers who make life-ending decisions.

And if that's not enough conflict of interest for a statutory guardian, the Kentucky Supreme Court ruled in 2004 that a public guardian may deprive life sustaining treatment from a man labeled mentally retarded, despite the financial conflict of interest for a state guardian of a ward on Medicaid.

And don't forget Professor Peter Singer, who holds an endowed chair in bioethics at Princeton, and believes that legal personhood should be subject to a cognitive test. Those who don't pass are eligible for killing if their families prefer, or for society's greater good. In fact, Arthur Caplan has repeatedly spoken about Terri Schiavo's autonomy, but I am including as an

attachment to my testimony an article from the Philadelphia Inquirer in which he supports a presumption of non-treatment in ICU for people in a persistent vegetative or minimally conscious state, and limiting the information and choices provided to patients and families. This is one example of a futility policy permitting the health care provider to make the decision about treatment.

In the face of these developments, the disability rights movement has expertise to bring. But we also have an attitude about disability that diverges from the mainstream, especially the mainstream of bioethics. Frankly, I think that's why we were deliberately excluded from the last decade of policy making conducted off the public radar screen, why the right-wing-left-wing script was so important to these bioethicists, no matter how untrue and exclusionary.

Basically, the bioethicists have warped the palliative care movement into a life-ending movement. They've had hundreds of millions of dollars to work with, and they've used it to build a steamroller that's decimating the civil and constitutional rights of people in guardianship. This affects more than the disability community of today, it affects everyone, directly or through family, sooner or later. There are rules being made for who lives and who dies, but the rule-making and the medical killing are happening behind closed doors. Many things are private family matters, like parental discipline of children, for example, until they go too far. It's time to call "time out," to go back to the table and talk about how to build a health care and legal system that respects us all.

On a more practical level, what can you do to help?

#### MEANINGFUL FEDERAL REVIEW

Under Medicare and Medicaid law, you could provide for meaningful federal review of contested third party decisions to withhold treatment in the absence of an advance directive or personally appointed surrogate. Uphold a clear and convincing evidence standard with teeth in it. Uphold a presumption for food and fluids.

#### CONGRESSIONAL STUDY

Ever since the Cruzan decision in 1990, people with disabilities, old and young, have been starved and dehydrated based on surrogate or health provider decisions, but we don't know who, why, how or what factors were involved. We also know that physicians are overruling patient autonomy and denying treatment under futility policies. You could ask for all hospitals to send you their futility policies. Congressional examination of the impact of existing policies is necessary.

#### STATE-BY-STATE REVIEW OF LAWS AND POLICIES

Funding for a disability-rights-based state-by-state review of guardianship and health care decisions laws is needed, along with comprehensive efforts to develop reforms to safeguard against non-voluntary and involuntary euthanasia.

#### PUBLIC EDUCATION BY PEOPLE WITH DISABILITIES

There should be funding for public education about the perspectives of people living with significant disabilities on the difference between end-of-life decisions and decisions to end the lives of disabled people who are not otherwise dying.

## OLMSTEAD IMPLEMENTATION, PASSAGE OF MICASSA

The civil rights of people with disabilities to long-term supports in the community under the U.S. Supreme Court decision in *Olmstead* should be implemented. We call for passage of the Medicaid Community Attendant Services and Supports Act, which would allow people receiving Medicaid funding to have a life in the community instead of being forced into a nursing home. This bill also includes consumer-directed options that maximize personal responsibility and reduce costs.

## SUSTAIN GOVERNMENT FUNDED HEALTH CARE PROGRAMS

Conservatives who honestly supported efforts to protect the life of Terri Schiavo should work on a bipartisan basis with moderates and liberals to ensure continued appropriate funding of Medicare and Medicaid. Thank you for defeating the latest round of proposed budget cuts that threaten to result in a less-public, but very real, increase in the numbers of deaths of older and disabled people, even more prolonged and agonizing than the one experienced by Terri Schiavo, through lack of access to needed healthcare. I can't help but note that much of the power of the end-of-life movement has come from the fact that Medicare did not cover prescription drugs, including pain relievers. It was pure extortion to require people to agree to forego curative treatment in order to get pain relief, and I've been terribly disturbed to see that the new Medicare prescription drug coverage does not include pain relieving medication, continuing the pattern of extortion that forces people to accept a potentially premature death in order to receive pain relief.

To conclude, regardless of our abilities or disabilities, none of us should feel that we have to die to have dignity, that we have to die to be relieved of pain, or that we should die to stop burdening our families or society. Cognitive abilities must not be allowed to determine personhood under the laws of the United States. Reject the script you have been given by the right to die and the right to life movements. Instead, listen to the disability movement. We are your advance guard, in anticipation of the aging of our society, with decades of experience in living with disability. We want to help build a society that respects and welcomes everyone.

<http://www.raggededgemagazine.com/schiavostatement.html>

## **Issues Surrounding Terri Schindler-Schiavo Are Disability Rights Issues, Say National Disability Organizations**

*Oct. 27, 2003* -- We, the undersigned, come together in support of Terri Schindler-Schiavo, and her human and civil rights. We are the national spokespersons for the rights of millions of Americans with disabilities whose voices are often not heard over the din of political and religious rhetoric. We come together for those who will be touched by disability in their lifetime and who will need our help to make their voices heard.

We call on the media to join with us in ensuring that the real story about Terri Schindler-Schiavo, and thousands like her, is told.

We ask the general public, who are clearly confused about what is best for Ms. Schindler-Schiavo and others like her, to read this joint statement, signed by national organizations and our allies, and then to act accordingly to signal their support for Terri Schindler-Schiavo. Terri Schindler-Schiavo is alive. She deserves nothing less than the full advantage of human and civil rights the rest of us are fortunate to enjoy as Americans. We will not rest until her most basic humanity is secure.

The "right to life" movement has embraced her as a cause to prove "sanctity of life." The "right to die" movement believes she is too disabled to live and therefore better off dead. Yet the life-and-death issues surrounding Terri Schindler-Schiavo are first and foremost disability rights issues -- issues which affect millions of Americans with disabilities, old and young.

Can she think? Hear? Communicate? These questions apply to thousands of people with disabilities who, like Ms. Schindler-Schiavo, cannot currently articulate their views and so must rely on others as substitute decision-makers. The law requires that a guardian's decision be based on written documentation or other clear and convincing evidence of her wishes. Her husband and guardian, Michael Schiavo, says she would not have wanted to live in her current condition, but there is no written documentation or compelling evidence of this. There is just his word.

Early on in Michael Schiavo's quest to remove his wife's source of nourishment, an independent guardian was appointed upon request by Schiavo's own attorney, George Felos. That guardian, attorney Richard Pearse, issued a report to the judge stating that Michael Schiavo was not a credible witness to his wife's end-of-life wishes because he waited several years before coming forward with the claim that she wanted to die. Pearse also noted that Michael Schiavo would benefit financially from her death. Pearse was quickly removed at the request of Felos.



Experts on the issue of guardianship point out that it is always desirable that a person in Terri Schindler-Schiavo's position have an independent representative who has no particular interest in the case other than her. Since the dismissal of Pearse in 1999, Terri Schindler-Schiavo has never been appointed another independent guardian. The law Gov. Jeb Bush has just signed calls for one now.

The peculiar series of events which have led up to the current debate seem to have avoided both the judge's scrutiny and media coverage. Michael Schiavo says his wife would not have wanted to live in her current condition. And under Florida law a spouse has the right to decide, though his powers are limited by the U. S. Constitution.

Michael Schiavo conveniently remembered Terri's alleged wishes only after the malpractice judgment was awarded. A review of court records shows that of the \$700,000 from a malpractice settlement Michael won that was to go for her care, over half has been spent on his legal fight to disconnect her feeding tube. Over \$200,000 of it has been paid to his attorney George Felos. Michael Schiavo has refused to let his wife receive therapy from a speech pathologist, a common type of rehabilitation available to people with brain injury. A prominent expert filed an affidavit that Terri Schindler-Schiavo can swallow her own saliva, and could potentially be weaned from the feeding tube and recover some speech, so that she could indicate her own wishes.

A recent report in the New York Times Sunday Magazine stated that after months or years with little sign of consciousness, people may still be capable of complex mental activity. The reporter, Carl Zimmer, wrote, "To the medical world, ...hundreds of thousands of ...Americans who suffer from impaired consciousness present a mystery." Whether Terri Schindler-Schiavo is -- or isn't -- capable of "high level thought" is not the real issue here. It is clear that she is conscious and responsive beyond mere reflexes, as has been demonstrated by her ability to track with her eyes, respond to verbal commands by physicians who examined her on video, and react to those she loves.

She has a severe brain injury, yet has not undergone the rehabilitation that is typically given to people with this type of disability. People with severe cognitive disabilities are devalued as lives not worth living. In truth, the lives of all of us with severe disabilities are often considered expendable. This is why we are speaking out.

Americans who have disabilities -- cognitive disabilities like Ms. Schindler-Schiavo -- have rights. Congress decided that in 1990 when it passed the Americans with Disabilities Act. Yet most of society does not consider that Terri Schindler-Schiavo has any rights other than the right to die. We believe she has a right to therapy and support; we believe the Americans with Disabilities Act requires that.

Consider David Jayne, a 42 year old man with ALS. Every five seconds, a ventilator on a cart next to his bed pumps air into his lungs. He is not able to move. Twelve years ago, Jayne would have dismissed this existence as a living hell. "Yes, I am very passionate about the Terri Schindler-Schiavo issue, because I live it," says Jayne, who was profiled in TIME Magazine in 2001. Jayne, like many of us, would have once said he could not imagine living in his current state. "If someone had told me I would be paralyzed and tethered to a ventilator, yet still find meaning in life, I would not have believed them." Today he says, "It is incredibly wrong for society to decide who lives or dies based on their opinions of what level of quality of life is worth living."

In this matter of living as a disabled person, those of us who live with disability, are the experts -- not husbands, not parents, not doctors. We know that life with a disability is worth living, and we know that what makes life awful for us is the attitude of "better off dead" that drives much of the thinking surrounding people like Terri Schindler-Schiavo.

The fear of disability and the resulting bigotry adhered to by most non-disabled Americans is often cited by people with disabilities as one of the most difficult barriers to overcome. In a recent column, Bill Press stated, "I wouldn't want to live like that, would you?" We respond: "like what?" Terri Schindler-Schiavo is characterized as "...a brain-damaged woman who has been kept alive artificially." Meant to signal horror, the concept has no real meaning to us who live by "artificial" means. Is a person on dialysis being kept alive artificially? Is a person taking insulin being kept alive artificially? Is a person who undergoes open-heart surgery, or cancer treatment, or intensive care in a hospital being kept alive artificially?

It is a well-known fact among those of us who live with disabilities that a feeding tube is a low-tech support, and people who use them can and do live full and meaningful lives. It was invented in the nineteenth century and relies on nothing more than gravity to make it work.

Terri Schindler-Schiavo is said to be in a "persistent vegetative state." But is she? In court, the medical experts were divided. Fl. Circuit Judge George Greer say she has not demonstrated sufficient actions to prove "cognitive function" because her actions were not "consistent" or "reproducible." But Florida law defines "PVS" as a condition in which there is no evidence of responsiveness. By ignoring Florida law, Judge Greer has violated her due process rights, as many of us asserted in our friend-of-the court briefs.

Historically, many people with disabilities such as autism, Down syndrome and cerebral palsy have been thought to be incapable of communication. Increasingly, yesterday's assumptions about inability are being thrown out when confronted with the reality of people exceeding the low expectations put on them by others.

In 1990, the Supreme Court held, in the *Cruzan* case, that the experts' subjective determinations of things like "persistent vegetative state" invite the very "quality of life" judgments that the Court found were inappropriate.

Terri Schindler-Schiavo's fate is entwined with all disabled people who rely on surrogates. If the legal standard in cases involving termination of life support is reduced to the point where Ms. Schindler-Schiavo's "quality of life" - as determined by others - justifies her death by starvation, then what protections exist for the thousands of us who cannot speak due to disabilities?

Discrimination against people with severe disabilities is part of our nation's history. Eugenacists advocated for the involuntary euthanasia of 60,000 "hopeless cases" of persons with disabilities in institutions in the last century, and urged the killing of "defective" children. Thousands in our nation were sterilized against their will because they were "defective". Infants born with disabilities have been denied lifesaving medical treatment. And people who become severely disabled, like Terri Schindler-Schiavo, are said to be better off dead.

The need for constitutional limits on the powers of surrogate decision makers is nowhere more clear than on a question as fundamental as life or death, because the consequences of abuse or misjudgment are both ultimate and irreversible. Treating people differently based on health or disability status violates the rights of people with disabilities under the ADA. Absent proof that it is truly the person's decision, withholding medical care based on the belief that he or she would rationally want to die because of a disability is discriminatory.

Due to bias against disability and ignorance about the support systems and successful coping strategies that preserve autonomy, meaning and pleasure in life, some physicians have decided that some deaths are more rational than others and that incompetent ill and disabled people do not deserve the same type of health care that "competent" people would receive. When health care providers deny people with severe cognitive disabilities the health care they need to live, we believe they are violating the Americans with Disabilities Act.

The belief that people with disabilities like Schindler-Schiavo's are "better off dead" is longstanding but wrong. It imperils us all. As spokespeople for millions of Americans with disabilities and their families, we stand with Terri Schindler-Schiavo to protect her civil and human rights as a living American. She requires the equal protection of the law.

**SIGNED:**

ADA Watch

ADAPT

AIMMM - Advancing Independence

Center for Self Determination

Center on Human Policy  
Citizens United Resisting Euthanasia (CURE)  
Disability Rights Center  
Disability Rights Education & Defense Fund  
Disability Rights Project of the Public Interest Law Center of Philadelphia.  
Hospice Patients Alliance  
National Catholic Partnership on Disability  
National Coalition for Disability Rights  
National Coalition on Self-Determination  
National Council on Independent Living  
National Disabled Students Union  
National Down Syndrome Congress  
National Organization on Disability  
National Spinal Cord Injury Association  
Not Dead Yet  
Self Advocates Becoming Empowered (SABE)  
TASH  
World Association of Persons with disAbilities  
World Institute on Disability

***Guest Opinion***

**All Lives Are Equal Under The Law**

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Terri Schiavo died on April 1. Her fate was a topic of intense debate for months, and it is clear now that her death will not end the dialogue. In fact, Terri Schiavo's death may propel end-of-life issues even further into public consciousness. If there is anything positive to emerge from her ordeal, perhaps it is that more Americans will consider having the difficult end-of-life conversation with all of their loved ones.

The case of Terri Schiavo raises a number of troubling questions for Americans. For people with disabilities and their families, the case represents a "slippery slope" and raises the possibility that the right to life of people with significant intellectual and/or physical disabilities might one day be questioned.

It was just 20 years ago that many of us were enmeshed in the "Baby Doe" case when the starvation and dehydration of a newborn infant with Down Syndrome exposed this all-too-common practice in the United States. In that case, two separate judges sanctioned the death of the infant, an infant whose life could have been saved without heroics. Although few would agree with those judges' rulings today, they were fiercely defended as a protecting a private matter between families and doctors back in the mid-1980s.

Today, there are thousands of people with disabilities who use feeding tubes. For them, a feeding tube is not life support or heroic intervention, but the normal way they get food and water. When they are hospitalized for any reason -- however minor -- they risk having their normal means of eating and drinking being classified as "extraordinary treatment" or "life support."

Few of us have enough experience with severe disability to make an informed choice in an advance directive, but clearly, having a significant disability does not mean you are "pre-dead." People with disabilities agree with the Americans with

Disabilities Act -- that "disability is a natural part of the human experience." Indeed, so is death.

The persistent vegetative state diagnosis is another matter, however, one fraught with unreliability. The fair and just allocation of health care and long term support resources is often in the back of our minds, whether we talk about it or not. These are ample reasons why we must put aside the partisan posturing and have an open and inclusive discussion of the issues at hand.

The disability community today is troubled by the possibility that Terri Schiavo's life -- and death -- may cause legal protections for people who have guardians to be dismantled, making it easier for guardians to kill by withholding food and water. There must be a way to balance a person's right to expressly refuse treatment against a person's right not to be deprived of life without due process of law. Due process of law must appreciate the wishes and interests of people with disabilities, even if their lives are devalued by other people. Today, we fear that is not the case.

Terri Schiavo's wishes were not documented, and her husband and family had many conflicts. Advocates for people with disabilities would never have wished to deprive Terri Schiavo of her right to self-determination regarding the end of her life, had her wishes been documented in a living will and/or power of attorney. But they were not.

Given these ambiguities, the disability community feels that the courts should have ruled on the side of sustaining her life, not allowing her to die. The disability community, from many years of grappling with these issues, feels that in such cases, it is best to assume that life is preferable over death. This is the position of 26 national disability groups, many of which represent people like Terri Schiavo who have guardians.

State laws governing surrogate decision-making vary and are often the result of well-funded advocacy from a narrow group of professionals, not involving the viewpoint of people with disabilities. When a guardian is needed -- particularly a state-appointed guardian -- the possibility for conflicts of interest is clear. Thus, the Schiavo case has focused attention on the need for a "federal floor" to protect people under guardianship. Research indicates that people with living wills and advance directives frequently change their minds when the time comes to implement those directives. Once people experience severe disability, their sense of horror about disability usually fades. We also know that people who "cannot speak for themselves" are often able to use assistive technologies that allow them to communicate their wishes, hopes, fears, and good-byes even if they can no longer speak. In today's climate, it might be even more important to write down what you do want than what you do not want.

In addition, we must, as a society, stop using the term "persistent vegetative state." Too many people with significant disabilities have been called "vegetables," and this needs to stop. It is beyond demeaning. It is dehumanizing. In fact, some of the people who use the term most freely are doctors, and what often comes next is a discussion of the death or warehousing of the individual with such a pejorative label.

For a person with serious disabilities, the debate should not be about whether or not they are going to "get better" some day. Disability is a fact of life, every day of our lives. Millions of Americans are disabled, and for millions more, it is just a matter of time. None of us is guaranteed an able body or mind for life.

People with disabilities sometimes have wonderful lives, and sometimes they have lousy lives. They are just like other Americans. Just because a person has a significant disability does not mean that he or she does not love life. It does not mean that they should be assumed to be better off dead.

It is time for a call to conscience to both the Right and the Left. Guardianship should not be a death ship. People like Terri Schiavo, people with disabilities, are persons under the law, and they deserve constitutional protection.

The disability community is grateful that so many in Congress stepped up to support Terri Schiavo's right to live, even though we are concerned about the precedent that was established. We would like to see Congress follow up with the same level of concern in making sure we can provide care and support for the millions of Americans with disabilities by supporting Medicaid Community Attendant Services and Supports Act, legislation that would allow thousands of adults with disabilities who have Medicaid funded services to have a life in their communities, not just stay to alive in an institution. We call on the Congress to ensure continued support for Medicaid and other programs people need; and we look forward to the passage of the Family Opportunity Act, to allow families of children with significant disabilities to buy into the Medicaid program in order to help their sons and daughters live at home in the community, rather than being banished to a nursing home or institution.

Terri Schiavo's case is every family's nightmare. But disability doesn't have to be a nightmare. Even if our nation disagrees on how we define compassion, we must certainly agree that all lives are equal under the law.

<http://www.philly.com/mld/inquirer/4437797.htm>  
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Penn hospital to limit its care in futile cases

Severely brain-damaged patients won't get certain treatments, as a rule.

By Stacey Burling

Inquirer Staff Writer

The Hospital of the University of Pennsylvania is taking another crack at one of medicine's thorniest issues: how to treat people who have no hope of recovery.

The hospital's ethics committee has approved unusual new guidelines that include limits on high-tech treatment for patients with severe brain damage.

Under the guidelines, intensive care would not routinely be given to patients in a persistent vegetative or minimally conscious state. Only patients who had explicitly requested such care would get it.

The guidelines, which will not be implemented for at least a year, also say what the hospital will do for patients, both when there is hope for recovery and, later, when the goal shifts to providing good "hygiene, preservation of dignity, and alleviation of discomfort or suffering."

The rules are meant to define good care, just as the hospital does for conditions such as asthma or diabetes.

"Over the last 20 to 30 years, medicine has evolved a notion that limits are taboo, that whatever patients want or demand, they have every right to expect," said Horace DeLisser, a pulmonary and critical-care doctor who also cochairs the ethics committee. "What we're saying is that we think that care is not simply about giving more machines, that care has to be tailored to these patients."

Communication with families about patient prognosis and treatment will remain an important part of care, he said, and an assertive family could probably successfully fight the new policy. Penn also has a conflict-resolution process and offers the option of transferring the patient to



another hospital.

About a quarter of deaths now occur in intensive-care units, said Robert Truog, professor of anesthesia and medical ethics at Harvard Medical School. More than half of those occur after withdrawal of life-sustaining treatment.

Although more than 90 percent of people say in surveys that they would not want to be kept alive in a vegetative state, less than a quarter make it clear in advance when they would want doctors to give up, said Robert Perkel, chairman of the ethics committee at Thomas Jefferson University Hospital.

Wesley J. Smith, a California lawyer and author of *The Culture of Death: The Assault on Medical Ethics in America*, is a longtime critic of hospital policies that limit care when doctors think patients lack sufficient quality of life. This approach is dangerous because it "creates a hierarchy of human worth," he said. "What is going on here is a statement that certain lives have less value than other lives, and that the values of the institution trump those of the patient."

Doctors who work in ICUs say they are sometimes asked to perform grotesque procedures on people who are capable of feeling little more than pain. CPR can break bones. It is almost impossible to insert certain types of intravenous lines in bodies twisted by a long period of brain damage, DeLisser said. "It approaches assault. You're really just attacking these patients."

Doctors and nurses go home after treating such patients feeling not only that they have done no good, but that they have caused pain, only to delay an inevitable death.

Under the new Penn guidelines, DeLisser said, if a patient in a persistent vegetative state - a step above coma - were transferred to the Hospital of the University of Pennsylvania with a fever, he would get the sorts of treatments he could receive as an outpatient: blood tests, antibiotics, a chest X-ray, urine tests. He might be admitted to a general medical bed. But, in the absence of an advance directive from the patient, he would not be admitted to an ICU. He would not be put on a ventilator or breathing machine. (If he were already on a ventilator, the hospital would not take him off.) He would not get surgery.

Doctors at HUP now use a hodgepodge of approaches, DeLisser said, but "for the most part... the unwritten approach is actually what we've written in the guidelines."

At Penn, there are one or two intractable conflicts each year, said John Hansen-Flaschen, chief of Penn's pulmonary, allergy and critical care division. The most recent involved an elderly woman

with many medical problems. She suffered a serious stroke after refusing amputation of a leg. The woman had been "rescued over and over again," but she was "dying from the outside in," Hansen-Flaschen said. Both legs had gangrene; she had large bed sores. "Portions of her body looked like a cadaver pulled out of a grave," he said. The family would not sign a do-not-resuscitate order. She eventually died after a failed resuscitation attempt.

Hospitals have wrestled with the controversial concept of medical futility for more than a decade. Many have decided that it is futile to try to define futility. A growing number have opted for creating a procedure for dealing with conflicts about withholding or withdrawing care, an approach the American Medical Association has endorsed. Massachusetts General Hospital, Children's Hospital of Boston, and, in this area, three hospitals in the Mercy Health System have developed such procedures. In Texas, hospital conflict-resolution procedures are now backed up by a state law.

But Lawrence Schneiderman, a medical ethicist at the University of California San Diego, says hospitals also need to define when that process is justified, as many California hospitals do. Most judge appropriateness of treatment on the basis of patient awareness and potential for appreciating the care.

Penn's guidelines, and another set of rules it has governing withholding or withdrawal of life support, do not use the word "futility." They do say, "The purpose of intensive life support is to sustain or restore a meaningful survival for the patient, where meaningful refers to a survival that can be valued and appreciated by the patient."

The weak point of virtually all policies is that hospital leaders fear they would lose a lawsuit if they denied care demanded by a family. They will rarely back doctors all the way, so there's little case law on the subject.

Cathy Mikus, associate counsel for the Mercy system, said that in the year since its policy went into effect, all disputes have been resolved. She is confident the hospital would support its staff if agreement could not be reached. "If we have to go all the way through this process," she said, "we have physicians who feel very, very strongly that the care is not appropriate under the circumstances."

Etienne Phipps, director of the medical ethics program at Albert Einstein Medical Center, doubts her hospital could successfully fight a family in "this current legal environment." She also doubts it would want to. It is "highly likely" the administration would side with the family, she said, "because of the values of the hospital toward supporting the patient and family values over everything."

The issue of when to limit care arose in the 1970s, after it became clear that life-sustaining treatments such as mechanical ventilation can sometimes be "more burdensome than beneficial," said Eric Krakauer, associate director of the palliative care service at Mass General.

Back in those days, however, doctors were the ones more likely to want to "do everything," and families of patients such as Karen Ann Quinlan were asking to pull back. At the same time, the patient empowerment movement was gaining steam, and doctors began paying more attention to patient and family wishes in medical decisions.

By the early 1990s, many doctors began to worry that some dying patients were getting too much care. Patients and their families, concerned that HMOs and money-conscious hospitals were trying to cut costs, were getting less trusting. Now, conflicts are more likely to be between families who want more and doctors who want less.

Arthur Caplan, director of Penn's Center for Bioethics, said doctors have compounded the problem by offering families a menu of choices.

"That's not the best way to approach the family," Caplan said, "because it makes the family feel responsible for ending the life of their loved one."

It's better to say, "In our best judgment, sadly, there's nothing more we can do. We're going to begin the process of stopping aggressive care."

Doctors could also head off disagreements by explaining life support better on the front end. "You should never start an intervention, a feeding tube, dialysis, where you haven't had a little bit of discussion about when you're going to stop it," Caplan said.

DeLisser says it's vital to define the type of care patients will get, no matter what, because families often fear the hospital will stop taking care of their loved one if they agree to limit life support. "Medicine, I don't think, has recognized that what patients and their families really want is... they don't want to be abandoned."

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